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Policy study

The establishment of personal assistance services in Montenegro

Coalition for Social Changes

Association of Youth with Disabilities of Montenegro
Juventas
The Monitoring Center CEMI

CEMI



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Foreword

The importance of establishment of personal assistance services as a support service to persons with disabilities was recognized by the Poverty Alleviation and Social Exclusion Strategy (PASIS). Specifically, the Strategy states that the most significant causes of poverty of persons with disabilities in Montenegro are, among others, low levels of education and lack of employment. One of the main causes to this is the lack of support services for this population, including the personal assistance.

Within the framework of the project “Strengthening advocacy function of CSOs in Montenegro through developing policy-oriented capacities of Coalition for Social Changes”, funded by the Delegation of the European Union in Montenegro, implemented by the Monitoring Center - CEMI in cooperation with Juventas and Cazas, a Coalition for Social Changes was formed, comprised by ten NGOs from Montenegro. The Coalition has prepared recommendations for the improvement of policies in the areas of health, social care, employment and education, through monitoring of the implementation of PASIS, field research and interviews with relevant institutions. As part of the project, a study “The establishment of personal assistance services in Montenegro”, has been prepared by the representatives of the Monitoring Center CEMI, Association of Youth with Disabilities of Montenegro and Juventas.

The aim of this brief is to identify the problems faced by persons with disabilities in Montenegro in terms of exercising their rights, in particular the establishment of the personal assistance services, as a key precondition on which rests the principle of independent living. The brief provides recommendations whose application would enable the establishment of a system of personal assistance in Montenegro and thus improve the current situation in this area. These recommendations are based on an analysis of models of personal assistance services that are being implemented in the region, as well as in some European countries, but which are also adapted to the specific social and economic determinants in Montenegro.

Qualitative and quantitative methods were used in the process of preparing this study. Further, for purposes of this study, CATI (computer-assisted telephone interviewing) survey was conducted on a sample of 1050 citizens of Montenegro, who were asked to express their views on health, education, levels of social exclusion and employment policies in Montenegro. Also, in-depth interviews with representatives of medical institutions and decision makers in this area were conducted.

The first part of the study includes the definition of notions of independent living and personal assistance services. Additionally, the impact of policy in this area on poverty alleviation and social exclusion of persons with disabilities is analyzed.

The second part of the study provides an analysis of how this issue is regulated in Montenegro. Legislative framework governing this area, that is laws and strategic documents that regulate the support services and personal assistance in Montenegro are analyzed. The study contains a strategic framework for the introduction of personal assistance services, basic objectives and measures envisaged by strategic documents, as well as institutions that are responsible for the implementation of recommendations and legal obligations in this area. Special emphasis is placed on provisions of PASIS and Strategy for integration of persons with disabilities.

The third and fourth part of the study contain a comparative analysis of the regulation of personal assistance services in the countries of the region (the Federation Bosnia and Herzegovina, the Republic of Slovenia, the Republic of Croatia and the Republic of Serbia), as well as in many European countries (Great Britain, the Kingdom of Norway, the Federal Republic of Germany, the Kingdom of Denmark, the Kingdom of Sweden, the Republic of Finland, the Kingdom of Netherlands and the Republic of Ireland).

In the **fifth part** of the study international standards and recommendations that regulate the service of personal assistance are presented, while the last section of the study contains conclusions and specific proposals for the introduction of personal assistance services in Montenegro, based on analysis of previous models and their applicability in our country.

I Introduction

Independence is a state of mind, not a muscle function...

Ingolf Oesterwitz

The **principle of independent living** of persons with disabilities includes independent decision-making in terms of meeting their needs, not independent physical implementation of daily activities. This approach stems from a social model of disability and is based on fundamental principles of: choice, decision making, control, responsibility and the right to make mistakes.¹ One of the basic preconditions for independent living of persons with disabilities is the existence of personal assistance services. Personal assistance enables persons with disabilities to obtain external support, which compensates for the things that seem difficult or impossible to exercise in independent living. Personal assistance service is defined according to specific and individual needs of each user, who defines and trains his/her assistant for meeting one's needs in the best way. This type of support is listed as a form of social support for persons with disabilities, as a rule number 4 of

¹ Based on social model, the problem rests in societal barriers, not in persons with disabilities. Disability is not viewed as a problem of an individual who needs treatment. Therefore, it is necessary to work on eradicating the barriers, as well as establishing a society with more equality in all aspects of life.

UN Standard Rules on the Equalization of Opportunities for persons with disabilities.² Thereat, a personal assistant is a person who assists a disabled person. Services are carried out according to specific needs of each user of personal assistance, whereby the user can specify the time and place where the services are to be provided, while a personal assistant provides assistance solely in the most convenient way to the user, and not in a way that is learned as a general rule. In countries where the personal assistance services are established, trainings for personal assistants are also provided, which includes mainly training on the needs of people with disabilities such as basic knowledge on helping tools, the social model of disability, protection of their own health in working with clients, as well as the management of service, ways of employment and the like.

Personal assistance service is established in European countries since the seventies. Initially, assistance was provided by private agencies, and referred to the help at home. Later, services were gradually expanded to include activities of social character.

Unfortunately, **the system of personal assistance controlled by the user, as well as law or legal act that regulates this is not established in Montenegro.**³ It is stated in the PASIS that the most important causes of poverty of persons with disabilities in Montenegro are, among others, low levels of education and employment, caused primarily by the lack of support services for this population, which includes personal assistance. The Strategy on integration of persons with disabilities in social life provides the adoption of laws and establishment of lacking services, including the personal assistance services. The introduction of this service would increase employment of persons with disabilities, as well as increase the number of persons who would attend regular schools, thus gaining the prerequisites for independent living and inclusion in social life.

Previous experience in the organization and functioning of support services for persons with disabilities in the social welfare system demonstrate their effectiveness and efficiency. Due to this, support services should become an indispensable content in the creation of a system of expanded rights and a mean of improving social care for persons with disabilities at both the local and national levels in Montenegro.

1.1. Notion of personal assistance and independent living

Support services are one of the main segments of the concept of extended rights and are very useful as they provide significant employment opportunities, as well as a mean of meeting the everyday needs of users. As mentioned above, personal assistance represents one of the basic prerequisites for independent living of persons with disabilities. In terms

² UN Standard Rules on the Equalization of Opportunities for persons with disabilities – General Assembly Resolution no. 48/96, December 29, 1993. Chapter I: Preconditions for equal participation, Rule 4: Support Services, Item 6: "States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities", item 7: "Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered."

³ Strategy on the integration of persons with disabilities in social life for the period 2008-2016, Government of Montenegro (published by the Ministry of work and social care, November 2007), page 22

of principles of independent living and community support services, it is important to note few definitions. Agnes Fletcher⁴ has defined independent living as “possibility for making choices in the definition of lifestyle and control over personal life,” while Gordana Rajkov⁵ states that “independent living of persons with disabilities does not mean physically independent performance of daily activities, but also implies that people with disabilities have a choice to make independent decisions about their life, choose a way of satisfying their needs, control the implementation of their decisions and choices, bearing the full responsibility for their decisions and choices made, but also to, as other people do, have the right to make mistakes. Independent Living is a philosophy and a movement of people with disabilities who work for equal opportunities, self-esteem and self-determination. Independent living does not consider that people with disabilities do not need anyone and that we can live in isolation. Independent living means that we want equal control and equal choices in independent living that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow in our families, to go to school in the place we live in, to use the same buses, to perform tasks that are consistent with our education and abilities. And most importantly, like everyone else we need to control our lives, to think and speak for ourselves.”⁶

Keywords of principle of independent living are: **the right to choose, the right to decide, the right to control, the right on responsibility and the right to make mistakes**, while the preconditions for the exercise of independent living are: **the possibility of obtaining relevant information, opportunities to share experiences with other people with disabilities, the existence of accessible transportation, affordable housing, affordable support services, architectural accessibility, access to communications, health and education services, access to employment and particularly significant, personal assistance services.**

Personal assistance includes provision of assistance to persons with disabilities to perform daily activities that cannot be done without the help of another person. The principle of personal assistance as a special type of social support for people with disabilities is defined in the UN Standard Rules on the Equalization of Opportunities of Persons with Disabilities (Rule No. 4). Thereat, a personal assistant is a person who assists a disabled person. Services are carried out according to specific needs of each user of personal assistance, whereby the user can specify the time and place where the services are to be provided, while a personal assistant provides assistance solely in the most convenient way to the user, and not in a way that is learned as a general rule.

In countries where the personal assistance services are established, trainings for personal assistants are also provided, which includes mainly training on the needs of people with

⁴ Agnes Fletcher was involved for seven years in the Committee on the Rights of Persons with Disabilities of the United Kingdom and has worked at the position of Director for Politics and Communications, and since October 2007. works as a consultant.

⁵ Gordana Rajkov is the deputy and the first person with a disability in the National Assembly of Serbia. She also works at the Center for Independent Living of Serbia, as a President of the association and coordinator for development and international cooperation.

⁶ Brochure “Personal assistance,” Humanitarian organization Partner, Banja Luka, 2008

disabilities such as basic knowledge on helping tools, the social model of disability, protection of their own health in working with clients, as well as the management of service, ways of employment and the like. The assistant must study the specific needs of each customer individually, whereby a special relationship of trust and acknowledgment must be nurtured, bearing in mind that assistant becomes an integral part of the private life of users. On the other hand, persons with disabilities, that is the users of personal assistance, choose a personal assistant and introduce him/her with one's needs, keep records on hours of work, respect the assistant as a worker and the like. Personal assistance service is established in European countries since the seventies. Initially, assistance was provided by private agencies, and referred to the help at home. Later, services were gradually expanded to include activities of social character.

II The analysis of current situation in Montenegro

2.1. Analysis of legislative framework

According to the census from 2003, Montenegro has 620,145 inhabitants (314,920 women and 305,225 men). In the age structure dominance of the younger population is observed (under 29 years of age). There are 4365 refugees from the republics of former Yugoslavia and 13,986 displaced persons from Kosovo. Health services are provided to general population through the state (on 3 levels, through a number of health facilities) and the private sector (117 health facilities).

Services provided by public health institutions are covered, in whole or in part, by the Health Care Fund, through taxes collected from employed citizens. Services provided by the private health system are paid for by the user, from personal funds.⁷

The same national census does not examine the issue of disability. On several occasions, there were initiatives and proposals from organizations of persons with disabilities to integrate this issue into the process of the census, but so far such initiatives were always rejected. Additionally, to this day issues of disability were not included in general national researches of various fields.

According to the World Health Organization (WHO), it is estimated that 10% of Montenegrin population are persons with disabilities. There is no precise and adequate data on persons with disabilities, especially on nature, type and levels of disability, as well as comprehensive statistics on persons with disabilities at the state level. Bodies and institutions that provide certain types of services to persons with disabilities maintain partial records on their beneficiaries.⁸

Fund for Pension and Disability Insurance (hereinafter FPD) of Montenegro manages

⁷ Publication: Swift assessment and response, Institute for Public Health of Montenegro, Podgorica, 2008

⁸ National report on persons with disability of Montenegro, 2005

data on 26.365 users of disability pension. The Employment Agency of Montenegro has data on 2.699 persons with disabilities who are registered as unemployed with this institution. FPDJ has data on 1.797 persons who receive caregiver's benefits, while the Ministry of Labour and Social Welfare has information that 7.203 persons receive social allowances and caregiver's benefits, 1.255 receive personal disability allowances on the basis of the Law on Social and Child Protection, while 158 receive allowances on the basis of veteran and disability protection regulation.

Employment Agency of Montenegro has data on 2,699 people with disabilities who are registered as unemployed for this service. The Pension Fund has information on 1797's right to compensation for support and care of another person, while the Ministry of Labour and Social Welfare has information that's eligible for assistance and care of another person has a 7203⁹ persons and 1255's personal disability under the Law on Social and Child Welfare, and the regulations on veteran and disability protection 158th

Ministry of Labour and Social Welfare manages the information on users of residential institutions for persons with disabilities, while the Ministry of Education and Sports has information on students attending special institutions, as well as information on students with disabilities who attend mainstream schools.

The Employment Agency of Montenegro¹⁰ implements a series of public works in the field of improving the quality of life of children with special needs and their families. In particular, additional support is provided to children during indoor, outdoor activities and during regular education, based on the **inclusive model**. Such assistance is implemented through 16 programs of public work, lasting from three to ten months in: Podgorica, Bijelo Polje, Pljevlja, Nikšić, Mojkovac, Rožaje and Herceg Novi. Contractors of these programs are nongovernmental organizations providing support to persons with disabilities, such as associations of parents of children with disabilities and schools attended by these children. In the abovementioned public works, 114 persons are involved as **"personal assistants"**. Their salaries are funded by the Employment Agency.

However, it is important to note that in this case personal assistants, as named by the Employment Agency, are in fact teaching assistants. As is hereinafter provided, it is necessary to make a clear distinction between the teaching assistants on the one side and personal assistants on the other.

This data is only on specialized services for persons with disabilities and due to its partiality, this data does not provide a complete insight into the status of persons with disabilities. It is clear that the data does not cover the entire population, and there is no statistics on the number of persons with disabilities using general services intended for the general population, as well as information on their accessibility to persons with disabilities.

⁹ The data refers to the number of beneficiaries, who exercised their right to assistance and care of other person in November, 2010.

¹⁰ The data was obtained through in-depth interviews with the representatives of the Employment Agency of Montenegro.

The Poverty Alleviation and Social Exclusion Strategy identifies that in Montenegro, nearly 60% of persons with disabilities live in poverty or below the poverty level.

In general, the method of assessing persons with disabilities by the former Commission for the categorization was based on the disease (impairment), not on individual needs. The estimate served as a basis for directing people with disabilities to special systems and services, but did not encourage their involvement in general integrated systems and services designed for all citizens.

The assessment of person with disability was performed by the Commission of the FPDI for the application for retirement and disability pension and assessment of physical damage, as well as the Ministry of Labour and Social Welfare that provided the exercise of the right to social and disability allowances as well as the caregiver's care. Given that both of the rights derived from the statutory definition of lack of ability to work, the estimates are based on determining of what persons with disabilities cannot do.

The classification of persons with disabilities shall be in type and degree of physical disability and pension fund in the system, the Law on Social Protection, the regulations on veteran and disability protection. This classification is the physical damage is often used as a basis for the exercise of certain rights and privileges, for example in customs and tax regulations. Determination of physical damage in the pension and disability insurance is regulated by the Ordinance on establishing the physical damage, and the system Veterans Act of War Veterans and Disability Protection and accompanying regulations.

The classification of persons with disabilities is determined by the type and degree of physical disability that often serves as a basis for the exercise of certain rights and privileges, such as in customs and tax regulations. Determination of physical damage in the system of pension and disability insurance is regulated by the Protocol on determining physical impairment, and in the system of veteran-disability protection through the Law on Disability Insurance and Protection of War Veterans ¹¹ and accompanying regulations.

In practice, there is a lot of controversy over the assessment of work ability of persons with intellectual disabilities and persons with autism. This is mostly due to the absence of clear criteria, the lack of a sufficient number of qualified staff with knowledge and skills etc.

Issues related to persons with disabilities in Montenegro are mainly regulated by the Ministry of Health, Ministry of Labour and Social Welfare and other ministries that take on some of the responsibilities by implementing activities from their jurisdiction. Some ministries, such as the Ministry of Culture and Ministry of Education and Sports, deal with issues related to disability through small working groups, while officials of other ministries deal with such issues through their regular activities.

¹¹ The Law on Disability Insurance and Protection of War Veterans („Official Gazette of Montenegro” number 69/03).

The Law on Social Welfare and Child Care establishes the quality of social services in a general manner, so there is no guarantee of quality of social services with the respect of the principle of user-control of services.

Social services are provided at the national and local levels. In the process of decentralization that is being implemented in Montenegro, some social services in the process of transformation have been delegated at local level, but local governments do not have the necessary human and financial resources to provide the optimum level of service quality in a standardized way across the country.

Amendments to the Law on Social Welfare and Child Care and the Law on local self-government did not include regulation of rational, sustainable and decentralized network of social services and their provision with standardized criteria and quality in all municipalities in Montenegro, with support from central authority where needed.

Currently in Montenegro, three day-care centers are organized in Nikšić, Pljevlja and Bijelo Polje. For persons and children with disabilities there are no other services which would enable them to participate and contribute to communities they live in. However, day-care center in Bijelo Polje operates as part of the Center for Social Work and represents the first alternative form of social protection for children with disabilities.

On the other hand, some services are provided by non-governmental organizations. There are: playhouses, legal and other counseling services, printing services in Braille, assistance through orthopedic tools, medical supplies, food, clothing and footwear. The scope and types of services are far below the minimum needs of the population of persons with disabilities, whose provision is often limited to the duration of the project through which they are funded, meaning that provision of such services is not sustainable. The Law on Social Welfare and Child Care foresees the provision of certain types of assistance to parents of children with disabilities, so that the child could remain in the family.

The social protection of persons with disabilities is regulated by: The Law on Social Welfare and Child Care, Pension and Disability Insurance Law, The Law on Ratification of the UN Convention on the Rights of Persons with Disabilities, The Law on Transport Benefits for Persons with Disabilities and the Law on the Movement of PWD with assistance dogs.

In Montenegro the system of personal assistance controlled by the user is not established, nor there are laws or legal acts that would regulate it.

However, it is important to distinguish between student teaching assistants and personal assistants. Specifically, student teaching assistants are people who help students in the process of taking classes, but they are not necessarily personal assistants. Personal assistants are people who help not only children but also adults with disabilities in the process of socialization, education, employment and housework.

Support services for persons with disabilities, including the personal assistance services are foreseen by the **National Strategy for the Integration of Persons with Disabilities** in the chapter concerning the education. However, it is important to distinguish between teaching assistants and personal assistants. Namely, teaching assistants¹² are persons who help students in the process of taking classes, but they are not necessarily personal assistants. On the other hand, personal assistants are persons who help not only children but also adults with disabilities in the processes of socialization, education, employment and housework.

Foreseen measures by the Strategy for the Integration of Persons with Disabilities, in the field of education, accentuate that it is necessary to **“establish support services, such as daycare centers, personal assistance, accessible transportation, interpreters of sign language etc.”**¹³

2.2. Compliance with international standards and recommendations of international organizations

Prohibition of all forms of discrimination is one of the key steps towards achieving greater degree of democracy and the achievement of the values of tolerance, equality and equal opportunities for all. **The European Convention for the Protection of Human Rights and Fundamental Freedoms**, is ratified in Montenegro, that is successively inherited from the State Union of Serbia and Montenegro, which ratified this document in December 2003. Key provision of the European Convention for the Protection of Human Rights and Fundamental Freedoms¹⁴ related to the prohibition of discrimination are Article 14 of the Convention and Article 1 of Protocol 12 of the Convention. The

¹² Laws regulating the field of education of children with disabilities are: Law on Primary Education and The Law on Education of Children with Special Needs

¹³ Strategy for the Integration of Persons with Disabilities, Government of Montenegro, Chapter 8.3, Education-measures, pages 29-31

¹⁴ Convention for the Protection of Human Rights and Fundamental Freedoms as amended by Protocols No. 11 and No. 14, accessed at <http://conventions.coe.int/treaty/en/treaties/html/005.htm>

said provisions prescribe that “The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.” At the same time, Article 1 of Protocol 12 establishes that “The enjoyment of any right set forth by law shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.”

UN Convention on the Rights of Persons with Disabilities¹⁵ has been adopted through the Law on ratification on July 15th, 2009. Article 19 of the Convention establishes that “States Parties to the convention need to recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.” Central to the Convention is the notion of independent living, which needs to be fully secured.

The Standard Rules on the Equalization of Opportunities for Persons with disabilities¹⁶, is a document also successively ratified in Montenegro, which was adopted in 1995 by the Federal Republic of Yugoslavia. Rule 4 of this document – Support services regulates that states should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights. The rule further sets that states should support the development and provision of personal assistance programs, which would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities. Finally, the document sets that such programs should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.

2.3 What has been done: the failures and shortcomings

Beside the fact that Montenegro has not yet enacted any laws or legal regulations which would govern the introduction and application of personal assistance services to persons with disabilities, to this day in Montenegro only one project was implemented which envisaged the introduction of such services. Namely, the Organization of the Blind of Nikšić, in cooperation with the organization “Plegije”, recently implemented a project “Personal assistance”, which aimed at: empowerment of persons with disabilities to participate actively in the life of community and the introduction of personal assistance services.

¹⁵ Convention on the right of persons with disabilities of UN, accessed at <http://www.un.org/disabilities/default.asp?id=150>

¹⁶ The Standard Rules on the Equalization of Opportunities for Persons with Disabilities – Adopted by the United Nations General Assembly, resolution number 48/96, of December 20, 1993

Specific objectives of the project were:

1. Empowering of persons with disabilities for independent living;
2. Educating persons with disabilities about their rights and opportunities;
3. Introducing persons with disabilities to assistance services and their significance;
4. Gaining experience on the implementation of personal assistance services in neighboring countries;
5. The establishment of personal assistance services for a certain number of persons with disabilities;
6. Raising the self-esteem of persons with disabilities.

The planned objectives of the project were achieved through the involvement and training of 8 personal assistants for 11 persons with disabilities. Although the original project plan envisaged 5 personal assistants for 15 service users, implementers based on the acquired knowledge and due to aggravating circumstances changed the initial idea, in order to ensure quality to the implementation of the project.¹⁷ Thereat, the total number of hours of assistance remained the same (5400h), but individual users instead of 60, received approximately 90 hours of assistance per month. The implementation of the project would help persons with disabilities overcome the many difficulties they encounter in everyday life, especially through personal assistance, while all project participants expressed interest in using such services if they were provided in our community.¹⁸

In terms of other projects that involve the provision of personal assistance services, municipality of Herceg Novi participated in financing of personal assistance to one beneficiary, through additional scholarship, while the Ministry of Education and Sports and the Ministry of Labour and Social Welfare through lump assistance provided to another beneficiary.

Although the outstanding pioneering efforts of NGOs aimed at improving the quality of life of persons with disabilities, including pilot projects for personal assistance were implemented, central issue of the whole process is the lack of legislation that would regulate this issue, further entailing the problem of systematic administration and jeopardizing the sustainability of the implemented projects.

The following text contains impressions of two persons with disabilities who have used the personal assistance services.

In Montenegro, two cases of using personal assistance services were recorded. Miroslava Mima Ivanović, second year student of the Law Faculty in Podgorica and Danijela Vušurović, third year student of Faculty of Philosophy in Nikšić – Department of Psychology, describe personal assistance as the most convenient way to exercise and achieve the right to independent living.¹⁹

¹⁷ Periodic report of the Personal assistance project, Organization of the Blind of Nikšić, Šavnik and Plužine, Nikšić 2010

¹⁸ Publication: „Personal assistance”, Organization of the Blind of Nikšić, Šavnik and Plužine, Nikšić 2010

¹⁹ Interviews with Miroslavom Mimom Ivanović and Danijelom Vušurović were published on December 8th, 2010.

Funding of personal assistant for Miroslava Ivanović was supported by the Ministry of Labour and Social Welfare and Ministry of Education and Sports through providing short-term assistance. At the same time, Miroslava was the beneficiary of scholarships from the Kotor municipality and “Ljubica and Tomo Lompar” Foundation. During the first year, Miroslava paid her assistant 200 euros per month, regardless of the number of working hours. Today, Miroslava pays her assistant 220 euros for 16 working days, whereat each additional working day is paid 10 euros. Miroslava’s assistant helps her in getting up and going to bed, dressing, showering, going to college, cafeteria and performing other duties (shopping, going to the doctor, college activities and other daily activities). Based on her daily duties, Miroslava’s personal assistant spends 2 to 6 hours a day with her.

Experiences of the other user of personal assistance are very similar. Specifically, Danijela Vušurović, for three years has two personal assistants, one of which is paid with the financial assistance provided by the municipality of Herceg Novi and the second assistant is financed for six months within the project that was implemented by NGOs “Organization of the Blind of Nikšić, Šavnik and Plužine” and „Plegije“. Danijela’s assistants receive a fixed salary of 250 euros a month, who spend with her 3 to 4 hours assisting her in daily activities.

Both beneficiaries of personal assistance consider that personal assistants are crucial for their independent living, as they are a requirement for independent exercise of their rights as persons with disabilities, while at the same time they are very important for the implementation of social model approach to persons with disabilities. Thanks to the assistant, they feel as “persons who independently make their own decisions and move where they want”.²⁰ Without the help of personal assistants, they would not be able to study and would not be involved in social life. The life of person with disability and life of her entire family, says Danijela, would be greatly eased if personal assistance services are established. The existence of a database on persons with disabilities who require personal assistance is necessary for proper establishment of this service and its adequate implementation.

„I think the State should provide training for personal assistants and establish personal assistance services. Furthermore, research should be conducted at the state level on the number of users and their needs, and based on that data plan training and number of personal assistants. At the same time, this field should be legally regulated.” – Miroslava Ivanović.

²⁰ Ibid.

„All people are equal and therefore should have the same rights. What separates us are our prejudices and it is up to us to overcome them and be equal” – Danijela Vušurovic.

III Comparative analysis of the countries from the region

3.1. Personal assistance in Bosnia and Herzegovina

The legislative framework which would provide independent living services for persons with disabilities is still not established in Bosnia and Herzegovina. A Unique disability policy as a framework document has been adopted at a national level, where personal assistance is identified as a service essential for persons with disabilities with the aim of ensuring independent living for these persons in the community. From such a uniform policy, each entity developed a text of their own Strategy for Equalization of Opportunities for Persons with Disabilities that identify personal assistance services. The draft Law on Social Protection of the Republika Srpska identifies personal assistance as support to persons with disabilities. The Law has not yet been passed by the competent Ministry, but its adoption is expected in the early 2011. Proposed Strategy for Equalization of Opportunities for Persons with Disabilities for 2010-2014, which was adopted by the Government of the Federation of Bosnia and Herzegovina on 07.09.2010, but that has not yet been reviewed or approved by the Federal Parliament, provides for the establishment of the Law on support services for persons with disabilities in 2012.

Some disability organizations are working towards establishing conditions for independent living, but implementation of these activities is still in the beginning phase. According to the data published in the Survey of estimating the capacity of institutions and organizations that provide assistance to persons with disabilities, 14 organizations provide these services in Bosnia and Herzegovina, and 4 in Republika Srpska. However, this data is not considered to be reliable, because this service is officially part of expanded social services in Banja Luka only, so the assumption is that these institutions only have the staff trained to provide care and assistance. Projects in Banja Luka have developed over time into expanded services of social protection, while in Sarajevo assistance services are provided as project activities.

Development of personal assistance services in Banja Luka was initiated with the project of reform of social protection system, implemented by the IBHI²¹ together with the Ministry of Health and Social Welfare and municipal administration of Banja Luka. During the year 2003, eighteen users were included in the project, of which twelve users

21 Initiative for better and humane inclusion, <http://www.ibhi.ba>;

were over 18 years old and six users were children. In collaboration with humanitarian organization “Partner”²² and the Center for Social Work, Banja Luka initiates the personal assistance services since year 2005 that is being provided to this day. Within the project framework, the extent of the provision of personal assistance services is regulated in such a way that users of personal assistance together with the social workers determine the number of hours of this service. Beneficiaries of personal assistance services in Banja Luka in 92% of cases are people aged between 26 and 65 years. This is the period of life when a person is employed, has a family and is engaged in significant scope of social activities and obligations.²³ 38% of users of personal assistance have obtained college degree, while in the total population of persons with disabilities there are significantly less university graduates.²⁴ This suggests that higher levels of education require greater socialization of users and higher familiarity with the personal assistance services.

Center for Social Work of Banja Luka assesses the number of beneficiaries (30% of number of persons who receive care and assistance) and determines standards for home care and personal assistance. At the level of Banja Luka, a protocol on financing of these services (home care and personal assistance) has been adopted in 2007, as well as monitoring system established.

The overall system of personal assistance is based on three elements:

- Financial funds guaranteed by the Law on Social Protection
- Additional services which persons with disabilities receive through Unions of users
- and through participation of family

On the basis of Article 44 of the Law on Vocational Rehabilitation, Training and Employment of Disabled, it is possible to cover the assistance at work through the Fund for vocational training and employment of disabled persons in Republika Srpska, although there are no records of submitting such requests.²⁵

3.2. Personal assistance in the Republic of Slovenia

Personal assistance services in the Republic of Slovenia are currently implemented mostly by nongovernmental organizations or organizations of persons with disabilities, through the development of experimental social programs funded by the Ministry of Labor, Family and Social Affairs of the Government of the Republic of Slovenia, and in part by the Foundation for the funding of organizations of persons with disabilities and humanitarian organizations as well as from the Slovenian lottery funds.

22 Humanitarian organization “Partner”, <http://www.ho-partner.rs.rs/en/index.htm>;

23 In Serbia, 61% of users were in the same age limit

24 12,4% according to the research Lazor, T.; Nešić, S. “From my angle” Resource center for persons with disabilities, Ecumenical humanitarian organization, Novi Sad, 2007.

25 Law on Vocational Rehabilitation, Training and Employment of Disabled (“Official Gazette of Republika Srpska number: 98/04)

Similar to personal assistant, a “family assistant” is generally considered to be one of the parents or other family member of person with disability, while the right to “family assistant” is guaranteed by the Law on Social Insurance.²⁶

At the initiative of the NGO YHG – Association for theory and culture of handicap,²⁷ amendments of the legislation of the Republic of Slovenia are being prepared. New law on personal assistance has been drafted, which regulates rights and obligations of users of assistance and assistants. The assistant provides help to person with disability initially in the house, then at the workplace, during education and integration into society. The law also provides support for persons with disability in carrying out activities that are directly related to their integration into society and which they cannot perform due to the nature and degree of disability. Additionally, the Law on personal assistance regulates the provision of independent living for as many persons with disabilities aged between 18 to 65 years who live outside special institutions and who themselves chose this service through their custodian or through an attorney. Public consultations and inter-sectoral coordination has been completed for this law as well as the Law on Long-term Care.²⁸ It is planned that these laws begin with implementation from 2013.

The draft of the new Law on Long-term care and insurance, inter alia, regulates the services of personal assistants.

Finally, the existing law on social protection, i.e. the Law on Social Insurance²⁹ is being amended which, inter alia, foresees the right to personal assistant.

3.3 Personal assistance in the Republic of Croatia

In Croatia, the project of personal assistance was initiated in 2006, with funds from the Ministry of the Family, Veterans' Affairs and Intergenerational Solidarity,³⁰ through organizations of persons with disabilities. Croatian Union of Associations of Persons with Disabilities³¹ provides education on personal assistance and according to their data, during the period between 2006 and 2009, 930 persons were included in the process of providing and training on personal assistance, of which 78 persons in 2006, 176 persons in 2007, 338 persons in 2008 and 338 persons in 2009. The entire process undertook internal and external evaluation and was assessed as most useful in the framework of social services.

„The Law on Personal assistance“ is being prepared, but since the Law on Social Welfare³² is being amended, its adoption is prolonged.

26 The Law on Social Insurance <http://www.uradni-list.si/1/objava.jsp?urlid=199254&stevilka=2484>

27 YHD - YHD - Association for theory and culture of handicap <http://www.yhd-drustvo.si/>;

28 The Law on Long-term Care

29 Proposal of the Law on Social Security Benefits [http://www.si-part.si/media/Predlog%20zakona%20o%20socialno%20varstvenih%20prispevkih_12_03_2010\(1\).pdf](http://www.si-part.si/media/Predlog%20zakona%20o%20socialno%20varstvenih%20prispevkih_12_03_2010(1).pdf)

30 Ministry of the Family, Veterans' Affairs and Intergenerational Solidarity, Croatia <http://www.mobms.hr/>;

31 Croatian Union of Associations of Persons with Disabilities, <http://www.soih.hr/>

32 The Law on Social Insurance <http://www.zakon.hr/z/222/Zakon-o-socijalnoj-skrbi>;

On the basis of provision of the “Law on Personal Assistance” all persons with severe physical disabilities who depend on assistance and care from other people are eligible for personal assistance services, as well as persons with visual impairments and persons with hearing loss if it causes mobility difficulties. The law also regulates the scope of personal assistance services under which the users receive 80 hours of monthly assistance. Personal assistants receive hourly net wage of 3.39 euros, while half of their working time is spent in organizations of persons with disabilities. Unlike Serbia and Slovenia, in Croatia personal assistance is financed from state resources without local government or other projects.

It is important to note that the assistant is usually a friend of the person with disability and that the assistant cannot be a member of the family. If the user cannot find the assistant from friends, then the user announces the job vacancy through the Employment Agency. Any person who applies for the job is interviewed by the user and is chosen based on the assessment of the user of personal assistance, in accordance with his/her needs.

3.4. Personal assistance in the Republic of Serbia

Service provided by personal assistants in the Republic of Serbia is not being implemented under state framework. The service was started as a project activity of the Center for Independent Living of PWDs Serbia in 2003³³, funded by the Irish Government and maintained to this day through funds from different donors.³⁴ Since 2007, some local authorities have recognized the advantages of this type of service and started providing funds for a number of assistants in Sombor and Smederevo, and since 2009 Jagodina and Leskovac. During a period of time the assistants were financed by municipalities of Zvezdara in Belgrade and Medijana in Nis.

Center for Independent Living of PWDs Serbia, in cooperation with the Ministry of Labor and Social Policy³⁵ and Oxford Policy Management team³⁶, prepared the standards for this type of services.³⁷ By these standards, people with various types of physical disability are entitled to personal assistance. Also, these standards establish that the users of the personal assistance services need to have an established disability of 80-100%. Personal assistance is provided minimally 30 hours per month and maximum 90 hours, regardless of the need of the user for longer assistance. The standards establish that users of personal assistance must be persons with disability from 20 to 75 years of age, with equal gender representation of users where at least 40% of users are female. Standards further establish that the users of personal assistance services can be persons with disability regardless of the education, which means users can be of different levels of education.

33 Center for independent living of PWDs Serbia, <http://www.cilrbija.org/ser/index.php>

34 SPAS – the price of independence <http://www.cilrbija.org/ebib/SPAS-Cena%20samostalnosti.pdf>
SPAS- independence experiences <http://www.cilrbija.org/ebib/SPAS-Iskustva%20samostalnosti.pdf>

35 Ministry of Labor and Social Policy <http://www.minrzs.gov.rs>;

36 Oxford Policy Management, <http://www.opml.co.uk/>;

37 Website of the Republic Institute for Social Protection – Minimum standard of services in social protection, http://www.zavodsz.gov.rs/index.php?option=com_content&task=view&id=131&Itemid=143;

The standards establish that users of personal assistance services can be persons with disabilities living alone, with their closer or wider family, whose members are not able to assist them with daily living (such as elderly parents and/or partners, etc). Users of personal assistance services can also be persons with disabilities who are not employed. In any case, it is important to note that it is necessary to give priority to persons who are already engaged in social activities, or expressed the desire and have potential to engage in such activities. Therefore, the reason by which potential users want to get a personal assistant is one of the essential criteria. In this sense, the advantage is given to users who estimate that personal assistance would provide them with: the new and/or further work engagement, education, greater independence from parents and family, social engagement and social communication. In accordance with the standards the user is in a position to recruit, train, organize, monitor and if necessary fire one's assistant, meaning that there are no specific criteria for the selection of assistant, but that the user at one's own discretion chooses a person to be his/her assistant. The price of personal assistance is also provided by the standards, amounting to 2 euros gross per hour of service.

The new draft Law on Social Protection refers to introduction of personal assistance services at the state level.

IV Experience from other countries

4.1. Personal assistance in Great Britain

Much of the assistance to persons with disabilities in the UK is provided through local governments and charitable associations. According to the legislation of Great Britain, there are two funding sources for the assistance to persons with disabilities: 1) local government and 2) the Fund for Independent Living at the national level. Although local governments are legally allowed to carry out direct payments, they are not obliged to do so. Local governments, i.e. social workers assess the required number of hours needed to assist the person with disability. This aid is used to cover personal assistance, home care and support to social activities. The intent here is to limit the employment of family members as personal assistants. User organizations are required to pay value-added taxes when hiring assistants for persons with disabilities, while this tax is not required when users employ assistants on their own.³⁸

Personal assistants do not have their own unions in the UK, while the minimum monetary compensation for their work is not established. Information about personal assistants and direct payments for their work are obtained from Centers for Independent Living.³⁹ The aim of this process is to encourage people to demonstrate and spread their ideas and to increase the interest for personal assistance services. This interest is spread

³⁸ Disability living allowance, official site of the Government of Great Britain

http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG_10011731

³⁹ National Centre for independent living, <http://www.ncil.org.uk/contentid103.html>;

not only through the Centers for Independent Living, but also through other local organizations of persons with disabilities. The competence of organizations of persons with disabilities is to continually inform people on new developments, through its media and specialized newspapers. Finally, there are mechanisms that allow people to appeal on various levels, while on the other hand there is no law regulating the status of personal assistants.

4.2. Personal assistance in the Kingdom of Norway

In the Kingdom of Norway, personal assistance is being implemented from 1990, at the initiative of the National Association of Persons with Mental Disabilities, as a project activity, and already in 2000 personal assistance was regulated by the Law on social services.⁴⁰ This law established that personal assistance should be directed not only on specific categories of persons with disabilities, but to include all persons with disabilities, guided with the criterion of “user controlled personal assistance”.⁴¹ “The White Paper” from 2007 provides the user with the right to choose who will employ his/her personal assistant.⁴²

The assessment of needs of persons with disabilities is undertaken according to the tradition system of home care, managed by the local authorities. State authorities offer support to local authorities in terms of financing of additional costs for this service, in the period of three years.⁴³ A large number of people (90%) who have used other assistance services, prior to the establishment of the personal assistance services, received more hours of the services (on average 20 hours per week). Personal assistants are employed in three ways: 1) rarely (due to the complicated paper work) through direct contact with the user – 9%, 2) the local authority, which gives them the control over the means of providing this assistance – 65%, 3) user cooperation (ULOPA) – 25%.⁴⁴

The users of personal assistance in the Kingdom of Norway are mostly persons with physical disability, while a small number of users (4%) are persons with mental disability. The scope of personal assistance services on a weekly basis is about 36 hours per user.

4.3. Personal Assistance in the Federal Republic of Germany

There are 6.7 million persons with disabilities living in Germany, of whom 69.1% are persons with physical disability. The largest part of social assistance given to persons with disabilities is provided by local authorities and charities. Organizations are required to pay union wages. Often, users employ workers on the black market; therefore these

⁴⁰ Ole Petter Askheim, Personal assistance service in Norway, Riga August 19th 2008

⁴¹ “user-controlled personal assistance”, Ole Petter Askheim, Personal assistance service in Norway, Riga August 19th 2008, page 4

⁴² Ole Petter Askheim, Personal assistance service in Norway, Riga August 19th 2008, page 1

⁴³ About 12 500 EUR in the first year and half of that sum in the following two years - Ole Petter Askheim, Personal assistance service in Norway, Riga August 19th 2008, page

⁴⁴ ULOPA cooperation for personal assistance, official webpage www.uloba.no; English version <http://www.uloba.no/templates/Page.aspx?id=223>

workers are not paid for their social security. Anybody except relatives can be employed as a personal assistant.⁴⁵ The most important prerequisite for a personal assistant job is open and unobtrusive approach to persons with disabilities. Services provided by personal assistants vary and include, among other things, help with personal hygiene, mobility assistance, as well as the assistance at home, work and during leisure time.

Personal assistance services are regulated in Germany by three laws: Book V of German 'Sozialgesetzbuch' regulates the access to "care services". The money is given to the service provided – usually a private charity organization. Based on the German Insurance Book XI 'Sozialgesetzbuch', the payments are made for organizations or individuals. The needs in this insurance system are determined by the assessment of functional impairment, and are carried out every 6 months and in exceptional cases every 3 months. Under this context, persons with disabilities are provided with 200€, 400€ and 1.150€ a month, whereas in exceptional cases this amount can be increased to 1.785€. The Law on social insurance identifies the same categories as Book XI, but also includes property assessment of the user. If a household has a monthly income of less than 1.000€, assistance is awarded according to the need. German model of assistance regarding the support to individual users is based on the existence of the Center for Independent Living, which informs the users of personal assistance services on all available programs. Book V of German 'Sozialgesetzbuch' guarantees the budget for persons with disabilities who require personal assistance in various areas of rehabilitation, everyday assistance, assistance at work, etc.⁴⁶

4.4. Personal assistance in the Kingdom of Denmark

Danish policy for persons with disabilities establishes and regulates the provision of personal assistance services to these persons. Very important note in this policy is that the person must be able to administer the scheme of personal assistance as an employer.⁴⁷ Personal assistance rules are regulated by the Law on Social Services, articles 95-95c, and include assistance in the social field, such as personal or practical assistance. Activities outside the home and monitoring of personal assistance services are regulated by rules on personal assistants at the Ministry of Employment, which covers the need for assistance in the workplace provided by assistants who were trained by this ministry. Personal assistance in Denmark is aimed at adults with serious and permanent physical and mental impairments who are in great need of assistance. There is no upper age limit for users of personal assistance.⁴⁸

The Kingdom of Denmark regulates that if an individual has a need for personal assistance at work, assistance can be provided for up to 20 hours per week. Personal assistance at work is an autonomous system that can be used in a situation where a person

45 Dr Mirosinka Dinkić, Jelena Momčilović, The price of independence, Belgrade, September 2005, page 17

46 German Social Law I - XII, Sozialgesetzbuch (SGB) I bis XII

47 Danish disability policy - Equal opportunities through dialogue, April 2002.

48 Framework for civil management of personal assistance, in Danish - Regelsættet om borgerstyret personlig assistance (BPA)

<http://nordisk.felagsmalaraduneyti.is/samarbeid/brukerstyrt-personlig-assistanse/danmark;>

has already been paid or received compensation for the work they perform on a daily basis. The existence of assistance at workplace provides to a person with disability equal opportunities with others in the labor market. The regulation identifies all persons with severe limitations of vision and hearing, physical disability and dyslexia. If an individual has combined disabilities, then he/she is awarded a personal assistant for up to 37 hours per week, corresponding to full-time employment. Income of personal assistant is approved by the Employment Agency.⁴⁹

4.5 Personal assistance in the Kingdom of Sweden

The Law on Social Insurance in the Kingdom of Sweden regulates that the local authorities must provide every citizen with a “reasonable quality of life”.⁵⁰ This includes home care services which are provided by local communities. The assistance needs to cover the costs of personal needs, costs related to performing household tasks, as well as costs related to participation in social activities. In other words, assistance is based on the overall assessment of the need of the recipient. Until 1987, the local authorities had the monopoly of the evaluation, financing and service delivery – usually all these processes were performed by one and the same social worker. In reaction to such ‘triple monopoly’, STIL⁵¹ engaged in activities that involve cooperation with the beneficiaries. This led to the implementation of a pilot project, with as many resources as local authorities intended for home care.

All other users are subject to the Law on Social Insurance, which obliges local authorities to provide certain services or pay a certain sum of money to these persons. The government determines the maximum price of one hour service, which is about 10.5% higher than average price in the country.⁵² General social welfare in the Kingdom of Sweden is provided to everyone, with the existence of special programs aimed at meeting the needs of persons with disabilities. One of the major points of the Law on Social Care (LLS), adopted in 1990 in Riskdagen is that persons with disabilities are entitled to free personal assistance.⁵³ Users enter into contracts with local authorities, private organizations, join into user cooperatives or employ assistants directly. Over 80% of persons with disabilities enter into contract with local authorities, less than 10% join into cooperatives, while others employ their own assistants or enter into contracts with private organizations. Outside user cooperatives, family members are not encouraged to be employed as personal assistants.

Swedish local authorities legally provide information about direct payment of personal

49 mr Olivera Mastikosa, Tatjana Gajić: „Experiences from foreign countries in providing social and other services in the community“, Humanitarian organization, Partner Banja Luka BIH, 2007 god

50 Socialtjänstlag, Article 4, Paragraph 1.

51 Personal assistance in order to live the life you want, STIL <http://www.stil.se/> , <http://www.independentliving.org/docs3/stileng.html>

52 This price includes administrative costs of training, costs for companions etc. (nearly one fifth of the total price is applicable to these costs). Employers are required to justify expenditures of resources, while user cooperatives manage the accounting services. Unused hours can be saved for use during the period of 6 months.

53 Swedish disability policy: Dignity and democracy, Sweden's official website. <http://www.sweden.se/eng/Home/Society/Accessibility/Facts/Swedish-disability-policy/>

assistants. Information provided by the organizations of persons with disabilities and user cooperation. Potential cooperative members must first pass a series of ten courses in all aspects of independent living, personal assistants, independent assessment of needs, negotiation with funders, recruitment, training, planning, supervision of assistants, the role of relatives, labor laws on health and safety, the responsibility for co-operation members, etc.. Kingdom of Sweden has strict laws, for example. Labor law and strong unions, and the release of assistants happens only in very serious cases, users are then required to pay various expenses.

Swedish local authorities provide information about direct payments of personal assistants. Such information is also provided by the organizations of persons with disabilities and user cooperatives.⁵⁴ Potential cooperatives must first pass a series of ten courses in all aspects of independent living, personal assistance, independent assessment of needs, negotiation with donors, recruitment, training, planning, supervision of assistants, the role of relatives, labor laws on health and safety, the responsibility for cooperation between members etc.⁵⁵

4.6 Personal assistance in the Republic of Finland

In the Republic of Finland, local authorities provide funds for the assistance. The need for care is determined by social workers, also at the local level. Standard payments include 40 hours a week, without weekends and night duties. Users who directly pay their personal assistants are considered employers who recruit and manage the work of their assistants. The employment is not limited; therefore, family members can be employed. In some cases, local authorities pay the fees and implement administrative tasks. Users are the ones who determine the assistants' wage. Assistants receive the same amount of compensation as employees of traditional municipal services for home care.

Helsinki Center for Independent Living publishes books, magazines, newspapers and distributes them to wider audience. The most important task of the Center is training of users, while the most important theme of its work is the philosophy of independent living. The service of personal assistance is not limited to certain types of disabilities or diagnosis, although it is important that the nature of disability is such that it can be better resolved through personal assistance services.⁵⁶

Personal assistance is regulated by the Law on social services, article 4-2, which primarily regulates practical care and training of personal assistants. Personal assistance service includes help in personal care, as well as assistance on every-day practical home activities. The training of the assistant is provided by the user, who has the option of

⁵⁴ STIL provides legal assistance to beneficiaries of the insurance, and covers costs of legal expertise when necessary.

⁵⁵ The emphasis here is on independent trainings of users with their assistants. STIL used to have a friendly system where old members supported new, but it was hardly sustainable. In cases of conflict with assistants STIL provides support.

⁵⁶ User managed personal assistance <http://nordisk.felagsmalaraduneyti.is/samarbeid/brukerstyrt-personlig-assistanse/norge>;

choosing the assistant, what the assistant will do and when the assistant will provide help to the user.

4.7. Personal assistance in the Kingdom of Netherlands

The legislation of the Kingdom of Netherlands does not allow employment of spouses as personal assistants, while other relatives can be employed as personal assistants. The user can enter into contracts with a service that provides personal assistance, or the user may be the employer. The User Unions are organized in the Kingdom of Netherlands, which provide information in writing form or by telephone. The system of direct payment is a novelty in the Kingdom of Netherlands, so formal trainings are not established, although the models of trainings are currently being prepared. Significant emphasis is placed on the difference between local authorized services for home care and direct payments of personal assistants, which should be the choice of the user.⁵⁷

The Kingdom of Netherlands is one of the countries with great number of budget users. Since 2001, these persons have the option of choosing between assistance services and funding from the budget for different types of assistance. Most of persons whose personal assistance is provided by the budget are persons with mental disabilities. 90% of assistance to persons with disabilities in the kingdom is comprised of help services.⁵⁸

4.8. Personal assistance in the Republic of Ireland

Personal assistance in the Republic of Ireland is identified by the Centers for Independent living, as an essential factor for independent living, and during the initial stages of its application the Centers for Independent Living dealt with the establishment of services that were controlled by the users. Persons with disabilities employ and train their personal assistants in accordance with their needs, and assume full responsibility for actions and consequences that derive from such training. After evaluating a personal assistant, the user agrees on the number of hours of personal assistance service on weekly basis. The personal assistance service in the Republic of Ireland is financed through Executive health services⁵⁹ in various parts of the country, currently managed by numerous centers for independent living.⁶⁰

There are 25 centers for independent living in the Republic of Ireland, managed at the local level by persons with disabilities. Personal assistance services are funded mostly by the Executive health services, while a part of services are funded through the Community Employment scheme.⁶¹ The user establishes a contract with one of the centers, and after

⁵⁷ Jos Huys, Direct payments systems in support of persons with disabilities in Europe, Strasbourg, 2009

⁵⁸ Assistance services are different from personal assistance services, because they are provided directly by health care workers.

⁵⁹ Health Services Executive (HSE), official website Assist Ireland http://www.assistireland.ie/eng/Information/Independent_Living/Personal_Assistance_Services/;

⁶⁰ Enable Ireland, <http://www.enableireland.ie/>; Irish Wheelchair Association (IWA) <http://www.iwa.ie/Default.aspx>;

⁶¹ Community Employment is an employment and training program which helps long-term unemployed people to re-enter the active workforce by breaking their experience of unemployment through a return to work rou-

training, employs a personal assistant alone or in cooperation with center for independent living. Currently, 20% of trainings for personal assistants are provided by the centers for independent living, while 80% is provided by the users. Essential to the independent living of each person with disability is the fact that they are allowed to manage their own personal assistance services, thereat ensuring that the personal assistance is paid for in accordance with the time plan (weekly or monthly, depending on the employer).⁶²

Financing of personal assistance is regulated in the Republic of Ireland only by regional contract (not by a law). Family members are rarely hired as personal assistants, because they are hired through Centers for Independent Living. Some organizations, e.g. Muscular Dystrophy Ireland manage the services offering support to home care, and in this case many employees are family members. However, this type of service does not fit the philosophy of independent living.⁶³

V International standards and recommendations

Personal assistance is identified by the **UN Convention on the Rights of Persons with Disabilities**.⁶⁴ Article 19 of the UN Convention on the Rights of Persons with Disabilities regulates that the authorities need to take effective and appropriate measures to facilitate full equality for persons with disabilities, and secure independent living for these persons. The Article 19 further states that all persons with disabilities need to have provided the access to personal assistance as a human right.

The Article 4 of this convention states that States parties to the convention must undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities, without discrimination of any kind on the basis of disability. The Article also regulates that States Parties will adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the Convention.” Further, independent living is a central theme and requires full provision, as regulated by the Convention.

Article 19 of the Convention regulates “Living independently and being included in the community”, and requires from the states Parties to the convention shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities the right to live in the community with choices equal to others, as well as their “full inclusion and participation in the community”.

tine. The program assists them to enhance and develop both their technical and personal skills which can then be used in the workplace.

Official website <http://www.fas.ie/en/communities/community+employment/default.htm>;

62 The maximum and minimum price of personal assistance service is not specified. On the other hand, hourly wage is provided, because some persons require all-day assistance (24 hours).

63 Nuala Crowe Taft, INFOSHEET IRELAND, 2009, Expertise center independent living

64 Official site UN ENABLE Rights and dignity of persons with disabilities <http://www.un.org/disabilities/default.asp?navid=13&pid=150>;

The **Standard Rules on the Equalization of Opportunities for Persons with Disabilities**, as morally political recommendations were adopted by the United Nations General Assembly in December 1993. The rule 4 – Support services, regulates that states should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities. The rule further regulates that personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.

The notion of independent living simply refers to the fact that persons with disabilities must have equal rights with other people, and that the requirements concerning the enjoyment of freedom of choice and independent living should be met. Independent living is a concept based on which persons with disabilities strive to achieve equal opportunities and full participation in society as equal citizens. Personal assistance is, for many persons with disabilities, the first and most important support in achieving independent living, and is a basis of independence and freedom for these persons.

This is often a fundamental prerequisite for achieving positions of equal opportunities, self-determination and thus independent living. Due to this, organizations parties to the European Network on Independent Living have decided to conduct a campaign to establish the Law on personal assistance services in the European Union.⁶⁵ These organizations require from governments of the States Parties and the European Parliament to start work immediately and ensure human rights and personal assistance for all who need it.

The **Strasbourg Declaration** was drafted in the European Parliament in Strasbourg in 1989. The Declaration is comprised of eleven points which identify personal assistance as an essential factor of independent living, which itself encompasses the whole area of human activities, e.g. housing, transport, access, education, employment, economic security and political influence. The Declaration states that personal assistance services are a human and civil right and must be provided at no cost to the user. „These services shall serve people with all types of disabilities, of all ages, on the basis of functional need, irrespective of personal wealth, income, marital and family status.“ Point three of the declaration states „services shall enable the user to participate in every aspect of life,“ and that „these services shall enable disabled people, if they so choose, to build up a personal and family life and fulfill all their responsibilities connected with this.“

Important recommendation provided in this Strasbourg Declaration identifies that personal assistance services must be available to persons with disabilities for anything up to 24 hours a day, 7 days a week and that the funding authority shall ensure that sufficient funds are available to the user for adequate support, counseling, training of the

⁶⁵ European Network on Independent Living, P.A. Law campaign-Stop the Difference, official site: www.enil.eu;

user and of the assistant, if deemed necessary by the user. In relation to the funding, it must include assistants' competitive wages and employment benefits, all legal and union required benefits, plus the administrative costs, as well as that it needs to be guaranteed regardless of funding source or local government arrangements. "The user should be free to appoint as personal assistants whoever s/he chooses, including family members." It is further advised that no individual should be placed in an institutionalized setting due to the lack of resources, high costs, sub-standard or non-existent services.

The Declaration concludes: "in furtherance of all the above, disabled people and their organizations must be decisively involved at all levels of policy making including planning, implementation and development."

VI Possible scenarios for the introduction of personal assistance services

6.1. Scenario I - Status quo

Lack of personal assistance services controlled by the user in Montenegro as well as laws or any legal acts that would regulate it, results in a denial of rights to persons with disabilities to an equal position in society, and therefore represents a violation of provisions of the Law on Anti-discrimination. On the basis of the Law on the prohibition of discrimination, in particular the Article 18, relating to the discrimination against persons with disabilities, states: "Under discrimination of a person with disability shall be especially deemed: preventing or hindering the access to health care, i.e. denial of the right to health care, regular medical treatment and medicines, rehabilitation means and measures, in accordance with their needs, denial of the right to marry, form a family and other rights from the field of matrimony and family relations, denial of the rights on schooling or education, denial of the right to work and the rights related to employment relations. Unavailability of access to facilities and areas used by the public to persons with reduced mobility and persons with disabilities, or preventing, restricting or hindering the use of the mentioned objects, in a manner not disproportionate to the burden on the legal subject who is obliged to provide it, is to be considered discrimination as defined by the paragraph 1 of this article. Discrimination of the person with disability exists also in the case when measures to remedy limitations or unequal position this person is facing on the basis of disability, are not taken.

Although the provision of support services, which include the personal assistance services, is foreseen by the National Strategy for the Integration of Persons with Disabilities to persons with disabilities, especially to children with disabilities, which includes the personal assistance services, the Government of Montenegro has not fulfilled

the legally binding obligations concerning the field of education. The specific objective of the Strategy in this area is the inclusion of all categories of children and adults with disabilities, in order to ensure the development of their potential, sense of dignity and personal values.⁶⁶

Given that the personal assistance services are not established on either the national or local levels, measures foreseen by the Strategy for the Integration of Persons with Disabilities have not been implemented. Although the system of personal assistance services has not been established, a number of persons with disabilities use the services of personal assistants.⁶⁷

The absence of this service will result in the fact that a number of people with disabilities, for their degree of disability, is unable to meet their needs without assistance, while others are unable to meet their needs because of the large number of barriers that society places on them. In this way, people with disabilities in Montenegro are not integrated into the social mainstream. At the same time, barriers to education and mobility, lack of adaptation of the environment, as well as the low level of awareness of opportunities for persons with disabilities and limited interest in special schools result in a high level of poverty in this population.

Due to the absence of this service, a certain number of persons with disabilities are unable to meet their needs, while others are unable to meet their needs because of the numerous barriers that they face in everyday life. In this way, persons with disabilities in Montenegro are not integrated into the social mainstream.⁶⁸ Consequently, barriers to education and mobility, the lack of adaptation of the environment, as well as the low level of awareness on opportunities for persons with disabilities and limited number of specializations in special schools result in high poverty levels of this population.

6.2. Scenario II – Establishment of a fully free service of personal assistance for all persons with disabilities in need of such service

The ideal solution for regulating this area in Montenegro is the adoption of laws and the establishment of a fully free personal assistance service for all persons with disabilities in who need it. This can be done in the same manner as in the Kingdom of Sweden. In this case, it would be necessary to legally provide that all persons with disabilities, who need personal assistance, are eligible for a personal assistant. This would prevent the discrimination against persons with disabilities and ensure equality among users,

⁶⁶ It is important to accentuate the difference between student teaching assistants and personal assistants. Student teaching assistants are persons who help students in the classroom learning process, but they are not necessarily personal assistants. On the other hand, personal assistants are persons who help not only children, but also adults with disabilities in the processes of socialization, education, employment and housekeeping.

⁶⁷ According to the data of the Association of Youth with Disabilities of Montenegro, currently two persons are users of personal assistance services. Namely, these are Danijela Vušurović, student of psychology and Miroslava Mima Ivanović, student of Law in Podgorica. See more in chapter 2.1

⁶⁸ According to the data of the Association of Youth with Disabilities of Montenegro, there are no adequate conditions for schooling of persons with disabilities due to the lack of adequate didactic materials and supplies and insignificant number of architecturally suitable regular schools.

regardless of their specific needs for personal assistance. At the same time, there would be no criteria or conditions to be met for the use of personal assistance services.

Personal assistance users would train their own assistants in accordance with their needs. Personal assistants would earn their salary through providing assistance to persons with disabilities in carrying out their daily activities, so that these persons can socialize more.

Within the scope of this scenario, and in accordance with the model of the Kingdom of Sweden, the work of assistant would be secured by the law in a manner by which the termination of employment would happen only in very serious cases. Funding for personal assistance services would be ensured from the state budget, and would not compromise the right to any other social benefit.

This model is seen as an ideal or best suited for people with disabilities. However, aware of the fact that due to the current economic situation and inability to meet financial obligations which the Government would have to fulfill by adopting such a legal framework, this model is not feasible in Montenegro. Consequently, as the most acceptable solution of this issue we propose the following model.

6.3. Scenario III – The most appropriate model of establishing personal assistance services in Montenegro

The adoption of the Law on personal assistance is of primary importance, and should include, above all, a comprehensive definition of personal assistance and the definition of the philosophy of independent living, which is to be achieved through the existence of personal assistance services. The criteria that determine the precise conditions, under which the persons with disabilities are entitled to the service of personal assistance, should be elaborated and defined in detail through by-laws. At the same time, the number of hours of personal assistance services should be precisely established in accordance with the daily duties, that is, with the level of inclusion of person with disabilities. The greater participation in social activities would enable persons with disabilities to pay back the money, through their contribution to the development of society.

The law on personal assistance should regulate that the users of personal assistance can be persons older than 18, thereat maintaining the equality of gender representation among users, with at least 40% of users being female. Additionally, an important criterion should be that the persons, who have a determined disability of 80% to 100%, must be provided with personal assistance. The minimum use of personal assistance services should be 30 hours a month, and the maximum would depend on the need for assistance, in accordance to the degree of social engagement of person with disability.

The criteria would further establish that the users of personal assistance service can be persons with disabilities with different levels of education. Also, the criteria would predict that the users of personal assistance can be persons with disabilities who live alone or with

their family, whose members are no longer able to assist them in their everyday activities (elderly parents and/or partners, employed parents and etc.). Users of personal assistance services would also be persons with disabilities who are not employed as well as those involved in various forms of employment.

At the same time, the desire of person with disability to obtain a personal assistant should be one of the essential criteria. This would imply that the engagement of a personal assistant is carried out exclusively on a voluntary basis of person with disability. Consequently, the advantage would be given to users who believe that personal assistance would provide them with: new and/or continual employment, education, greater autonomy, independence from parents and family, social engagement and social communication. It is very important to legally regulate the fact that the assistant is chosen by the person with disability, not by a member of the family. If the user cannot find a suitable assistant, then the person with disability announces the job position or looks for an unemployed person through the Employment Agency of Montenegro.⁶⁹ Any person that applies for this job position will go through an interview with the user.⁷⁰ The selection is based on the assessment of the user of personal assistance, in accordance with his/her needs. The price of personal assistance should also be regulated in the by-laws, with the gross payment of 2 euros per hour of service.

Given that the personal assistance service requires financial expenditure by the Government, this model suggests that the funding for personal assistance should be provided from the social welfare system, and that the funds currently allocated from the budget on behalf of the Annex on carer's help,⁷¹ should be diverted to the Fund for financing personal assistance. This is particularly important because the goal of the right to assistance is support to independent living, and not the improvement of material situation of people with disabilities. However, given the fact that a significant number of persons with disabilities use these funds to improve their financial position, it is expected that the idea of financing the personal assistance in this manner would evoke significant disapprobation from persons with disabilities.

Baring in mind that the personal assistance service is envisaged exclusively as a service controlled by the user on a voluntary basis, this scenario suggests that the funds earmarked on behalf of the Annex on carer's help, in other words, the funds opting for long-term care and assistance from social security, should be diverted to some extent, to the Fund for financing of personal assistance, in accordance with the number of people with disabilities who express their need for personal assistant. Since there can be no interference with vested rights, current users of carer's allowance would express whether they need and want assistance or simply do not want to relinquish the funds they receive under the said

⁶⁹ In this case, the Employment Agency shall include the personal assistant position in the occupational category.

⁷⁰ Article 15 of the Labor Law from 2008 „Employer is a domestic or foreign legal or physical person, or part of the foreign legal or physical person that signs the labor contract with the employee

⁷¹ In November 2010 in Montenegro, there were 7 203 persons with allowance for carer's help, and during the 2010 the Ministry of Labour and Social Welfare provided 5.131.090 euros for long-term care

conditions. In other words, there would be no possibility for persons with disability to exercise multiple rights under the same basis. In order to access personal assistance services, potential users would have to provide to the local Office for Persons with Disabilities ⁷² a certificate from the Center for Social Work, confirming that they are not exercising the right to carer's allowance.

Further, the criteria would identify the conditions under which persons with disabilities would contribute to the costs of personal assistance services. In this way, the users whose income is greater than the average wage in Montenegro would finance 10% of the monthly amount that is paid to the assistant.

Since the Department of Employment implement programs aimed at active employment policy measures, and implemented for persons with disabilities and other individuals with barriers to employment, with the aim of increasing personal competence of these persons, for successful integration into the labor market, to ensure that persons with disabilities who participate in this program, services, personal assistance in attending the program could be paid from the Fund for vocational rehabilitation and employment of persons with disabilities. Of course in this case is important to respect the criteria that need to meet people that would use personal assistance services. At the same time, it is important to regulate by law that the time refers to the activities assistant in the work during working hours users be financed from sources that are intended for teaching assistants in the work, not from the means of personal assistance. ⁷³

The law should provide that part of the costs should be covered by local government in whose territory person with disability resides and works. This would also lessen the financial expenditures from the state budget. Given that the Employment Agency implements programs aimed at active employment policies in relation to persons with disabilities and other individuals, with the aim of increasing personal competences of these persons, personal assistance services can be provided to persons who participate in this program from the Fund for vocational rehabilitation and employment of persons with disabilities. During this process, it is important to adhere to the criterion that needs to be met by a person that would use personal assistance services. Withal, it is important to legally regulate funding for work assistant's activities, which should be provided from sources intended for work assistants, not from the funds for personal assistance.

In order to better coordinate the implementation of the Law on personal assistance, it is necessary to establish a **Department for the rights of persons with disabilities**, as a separate organizational unit of the Ministry of Labour and Social Welfare. The jurisdiction of this department would include all activities related to social and labor protection of persons with disabilities. The sector would prepare policies for the promotion of the rights of persons with disabilities, in cooperation with other stakeholders. Further, it would be necessary to establish a special **Bureau for personal assistance** within this department,

⁷² See more below

⁷³ The Law on employment and vocational rehabilitation of persons with disabilities identifies the work assistants who do not have to be personal assistants. The obligations of these assistants would be regulated through bylaws.

with primary responsibility of monitoring the implementation of the Law on personal assistance and ensuring conditions for its implementation. This bureau would employ five people, headed by the Chief and deputy Chief, while other employees would coordinate provision of personal assistance services for central, southern and northern regions of Montenegro. Each of these positions can be held by persons with disabilities, while their wages can be subsidized by the Fund for vocational rehabilitation and employment of persons with disabilities.

The local governments within the Secretariat for Social Affairs should establish branch offices for persons with disabilities. These offices would oversee the expenditure of funds from the municipal budget for the service of personal assistance at the local level, monitor the law enforcement at the local level, educate the users and assistants at a quarterly year period and submit reports to coordinators in charge of providing personal assistance services. After the training sessions, teaching assistants would receive a certificate proving that they have successfully completed the training, in order to avoid the abuse of user's choice of assistants (such as employment of family members, etc.). Finally, these offices would sign contracts on the financing of personal assistance services with users, while users would sign a contract with certified assistants for provision of the personal assistance.⁷⁴

VII Conclusion and recommendations for the establishment of personal assistance services

Montenegrin Constitution protects the rights of persons with disabilities. Although the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol were ratified in the previous period, as well as that the Strategy for the Integration of Persons with Disabilities for the period 2008-2016 was adopted by the Government and several laws that deal with their needs, the status of persons with disabilities in Montenegro is still at an unsatisfactory level.

Social inclusion of persons with disabilities (access to social services, employment, assistance to dependents and proper health care) is at a low level, while persons with disabilities still face discrimination in our society.

Previous activities that are performed in hospital to establish personal assistance services, as one of the key prerequisites for independent living of persons with disabilities and improving their financial status, have the effect of the following

Former activities that were implemented with the aim of establishing personal assistance services, as one of the key prerequisites for independent living of persons with disabilities and improving their financial status, have achieved following:

⁷⁴ On the basis of the Article 165 of the Labor Law, "The employer may conclude a service contract with a person for the purpose of performing the activities outside the business activity of the employer, the subject of which is independent development and repair of a certain object, independent performance of certain physical or intellectual work."

- o the lack of personal assistance system in Montenegro denies the status of equality in society to persons with disabilities;
- o given that the personal assistance services are not established on national and local levels, the measures foreseen by the Strategy for the Integration of Persons with Disabilities have not been implemented;
- o withal, barriers in education and mobility, unsuitability of the environment, as well as the low level of citizens' awareness on capabilities of persons with disabilities and limited number of occupations in special schools, result in high levels of poverty of this population

To the end of meeting international standards and recommendations of international organizations in the field of disability, as well as a comprehensive implementation of existing laws governing the rights of persons with disabilities, the Poverty Alleviation and Social Exclusion Strategy as well as the national Strategy for the Integration of Persons with Disabilities, it is necessary to:

- o Adopt the law on personal assistance and establish a service that would meet the criteria, precisely defined by bylaws;
- o Provide by law the financing of personal assistance services, by reallocating funds intended for payment of increments for aid and care of other person, into a special fund for financing personal assistance, as well as through participatory financing from various entities (local governments, users of personal assistance and resources of the Fund for professional rehabilitation and employment of persons with disabilities, contained within the Employment Agency of Montenegro);
- o Establish a department for the rights of persons with disabilities within the Ministry of Labour and Social Welfare, as a separate organizational unit of the Ministry. The competence of this department would include all activities related to social and labor protection of persons with disabilities;
- o Establish a special department for personal assistance, with primary responsibility of monitoring the implementation of the Law on personal assistance and ensuring the conditions for its implementation;
- o Set up offices for persons with disabilities within the Secretariat for Social Affairs, which would oversee the expenditure of funds from the municipal budget for personal assistance services at the local level, monitor the law enforcement at the local level, quarterly educate the users and assistants and submit reports to coordinators of personal assistance services, employed by the Department for personal assistance at the Ministry of Labor and Social Welfare.

The establishment of personal assistance services in Montenegro is very important because it would empower persons with disabilities to be equally involved in the social life of Montenegro. The establishment of this service and adequate normative framework would represent an approximation to European standards in the process of integration, and recognition of Montenegro as a state that respects human rights and provides equal opportunities to all citizens. Moreover, this line of action would increase employment in the country and reduce the poverty rates of the population.

About organizations

Coalition for Social Changes was established on the 15th of December 2009, among ten leading organizations of civil society in the area of health, social protection, labor market and education: The Monitoring Center, AD Center Equista, Center for Civic Education, Juventas, CAZAS, Institute for Social inclusion, Pedagogical Center of Montenegro, Montenegrin Association of Youth with Disabilities, Association of parents of Children with Disabilities „Sunbeam“. The Coalition is open for who all interested organizations of civil society, dealing with problems of poverty and social exclusion, can freely join. Main aim of forming of the Coalition is contribution to strengthening of advocacy capacities and watchdog functions of civil society organizations in Montenegro, in order to influence creation of policies and laws in the area of education, labor market, social and children's protection.

Association of Youth with Disabilities of Montenegro is a non-governmental organization, registered on October 22, 2001. It gathers youth with all kinds of physical and sensor disabilities (cross-disability approach) as well as non-disabled people willing to participate in activities of the future co-existence and integration. It is a non-profit organization, founded firstly to provide psychosocial support, solving numerous and complex problems that disabled youth encounter daily, as well as creation of educational conditions for College and University opportunities. Vision of AYDM - For youth with disabilities, without barriers! Mission of AYDM: Association of Youth with Disabilities promotes equal position of youth with physical and sensor disabilities in society through initiatives for establishing legal, educational, cultural and social frame that enables it. The Association implements several programs and projects, such as the Program for education, Program for schooling and assigning of guide and assistance dogs, Legal Program and antidiscrimination, Program of personal empowerment of persons with disabilities, as well as projects Monitoring and education of rights of persons with disabilities and Student services.

Juventas

Juventas is a non-profit organization established on January 29th, 1996 in Podgorica. Juventas envisages Montenegro as a stable, democratic society in which young people can freely express utilize their potential. Some of the goals of Juventas are: to stimulate critical thinking and develop a culture of dialogue, promotion of culture, peace, tolerance and peaceful conflict resolution, promotion of human rights, healthy lifestyles, and fight against drug abuse. More information at www.juventas.co.me

The Monitoring Center – CEMI is a nongovernmental, non-profitable organization founded in May 2000, whose main goal is to provide infrastructural and expert support for continuous monitoring of the process of transition in Montenegro. CEMI envisages Montenegro as a land of free citizens, the rule of law, social justice and equal opportunities.

The mission of CEMI is to continuously provide support to reforms and strengthening of institutions of political system and civil society organizations, by proposing and monitoring the implementation of public policies in the fields of human rights and freedoms, fight against corruption and Euro-Atlantic integration of Montenegro. CEMI implements its activities through three programs: Democratization and human rights, Fight against corruption and European Integration, while the organizational structure consists of four departments: Public policy research department, Legal department, Public opinion survey department and Public Relations Department. More information at: www.cemi.org.me

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